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ABSTRACT

An ecological model for service and advocacy for handicapped children through a residential diagnostic center is presented. Such a model is explained to provide a meaningful interrelationship of varied resources and agencies at the local, state, and federal level with a focus on the generic program. Four positive interfacing functions relating to parent problems (such as lack of understanding about the child's handicap and inadequate knowledge upon which to base decisions) are discussed. Five basic service phases (referral, admission, diagnosis, planning and implementation) are described, and a case study is provided to illustrate the model's operation. Among other services ascribed to the ecologically oriented agency are workshops for parents and mediation between families and agencies. (CL)

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AN ECOLOGICAL MODEL FOR EDUCATION AND CHILD ADVOCACY FOR HANDICAPPED CHILDREN: the Role of the Residential Diagnostic Center

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With the passage of 94 - 142 at the federal level and concurrent passage of compatable laws at the state level the handicapped child is entering the halcyon days of services for the disabled. The birth into this new era, however, is not completed without pain and trauma for the child, his family, his school and community. In August, 1977, a unique, experimental program was begun at the Texas Elks Foundation, Luling, Texas, in order to alleviate some of the birth pangs. This paper focuses on the tenets and philosophies arising from that program: a short term residential diagnostic center for multiply handicapped children below the age of eighteen.

Definition of Terms

In this instance "ecological" means the relationship of the organism to his environment - how they interact - how they are dependent and independent one of the other. The organism is the handicapped child existing within his environment that contains parents, school, neighborhood, community, state and federal agencies. All of these now have some bearing on each individual handicapped child regardless of where he lives.

"Advocacy" in this case means standing up for, or being a spokesman for someone else. The advocate for the handicapped child must do more than just speak for that child. He must be involved in a counselling role. He becomes a liaison between handicapped child and environment because he is the professional who should possess the necessary knowledge, skills, and experience to assist the child and family in viable decision making. The assumption that parents must make the final decision is correct; the assumption that they must do this alone is erroneous.

An analogous situation is that of the patient in need of an operation. It is the patient who signs the permission to operate. This is only done, however, after receiving a myriad of professional inputs from health advocates

(physician, technicians, etc.). In the same manner it is the parent who gives final permission for placement in special education classroom after receiving numerous inputs from educational advocates (teachers diagnosticians, etc.).

In an ecological approach, then, the advocate serves not only as spokesman but also as the "interface" between the child and his environment. "Interface" is defined as the boundary or connection between two things. In an ecological approach to services the advocate is the interface, or the boundary between the child and his environment. It is a boundary that serves not to shut out but rather to pull in, to filter, and to bring to the child and his family the essential agencies and delivery systems needed for development toward full potential.

* * *

In the April, 1978, issue of Exceptional Children Nicholas Hobbs introduced the idea of an ecological model in which the "interconnectedness" of the lives of children is emphasized; a model in which the parents are ultimately responsible as the "experts" on their child with the professionals providing contributions to the decision making. It is in this area of decision making that the ecological model for services becomes mandatory.

On one hand the handicapped child and his parent are faced with a wide range of needs for securing the child's complete fruition. (Diagram 1) On the other hand there are available to the parent and the child a wide range of agencies, services, and benefits that can help to fulfill the needs. (Diagram 2)

Diagram 1

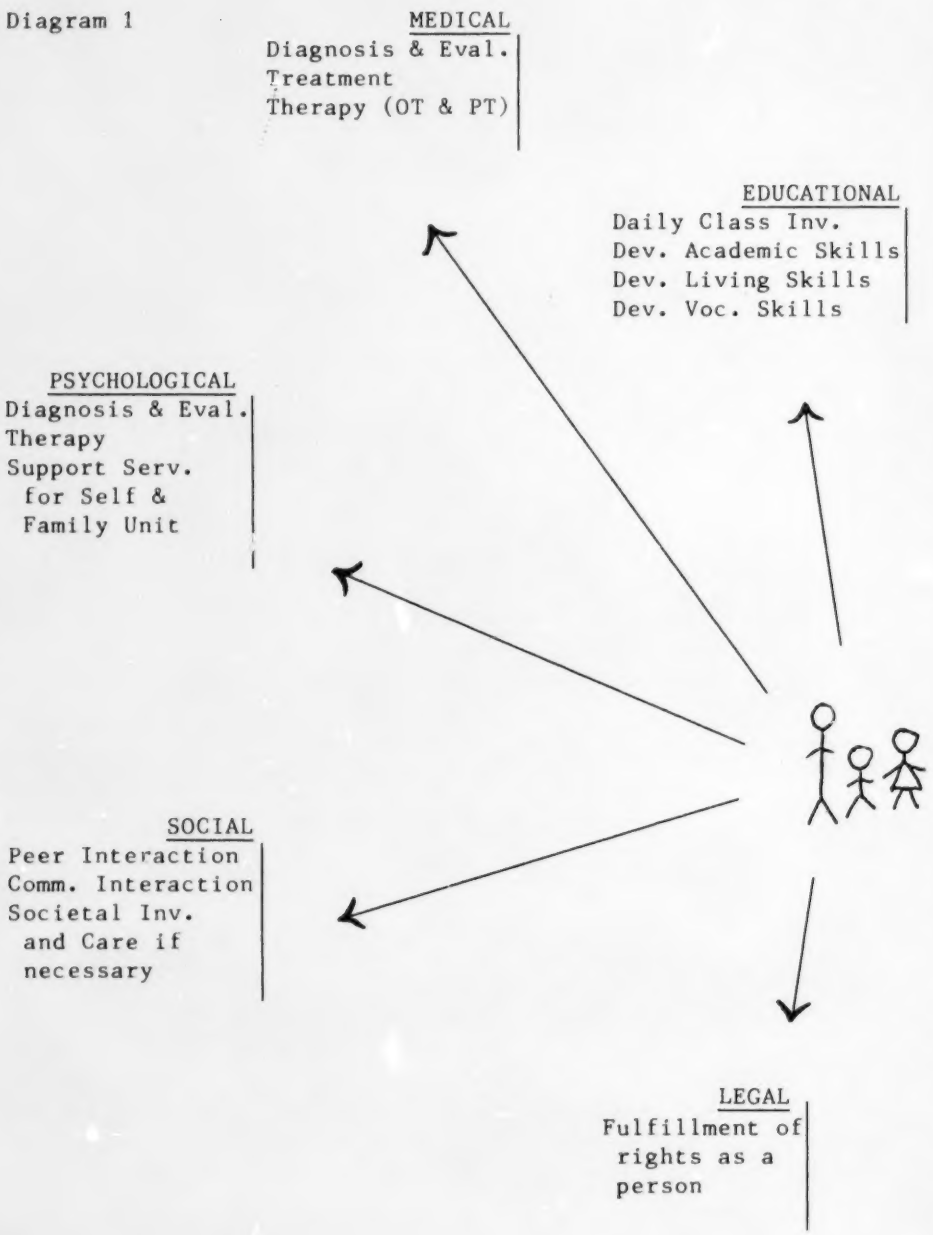

MEDICAL
Diagnosis & Eval.
Treatment
Therapy (OT & PT)
EDUCATIONAL
Daily Class Inv.
Dev. Academic Skills
Dev. Living Skills
Dev. Voc. Skills
PSYCHOLOGICAL
Diagnosis & Eval.
Therapy
Support Serv.
for Self &
Family Unit
SOCIAL
Peer Interaction
Comm. Interaction
Societal Inv.
and Care if
necessary
LEGAL
Fulfillment of
rights as a
person

Diagram 2

MEDICAL

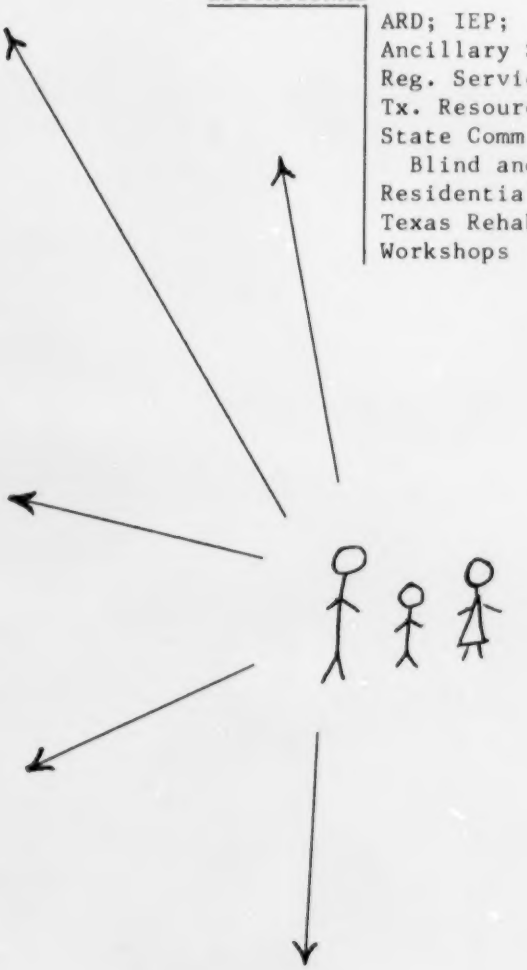
Clinics; Med. Centers;
Rehab. Centers; State Comm.
for Blind & Deaf; State Health Dept;
CCD; Medicaid

EDUCATIONAL

ARD; IEP;
Ancillary Services;
Reg. Service Centers;
Tx. Resource Services;
State Comm. for
Blind and Deaf;
Residential Settings;
Texas Rehab. Comm;
Workshops

PSYCHOLOGICAL

MH MR; State
Hospitals;
Children's Centers;
Private Treatment
Centers; Workshops



SOCIAL

MH MR; Day Care;
Camps; Parent Groups;
ARC; ACLD; ICFMR Programs;
CEC; SSI; Medicaid;
Y Programs; Dept. Human
Resources; Church Groups;
Workshops

LEGAL

Advocacy Inc.;
PL 94-142;
Sec 504 Voc
Rehab Act (1973);
Dept Human Resources;
Workshops

Four major problems exist. The first is that the parents most probably do not totally understand the child's handicap and the subsequent need package inherent within the particular handicap.

The second is that the parents usually do not have adequate basal knowledge to make wise decisions about fulfilling the child's need package; i.e. which needs are most pertinent, which are easiest to meet, where are they secured, etc.

A third problem that exists in many cases is that traditionally the family resorts to the school and/or family doctor for direction. Unfortunately the latter of these is probably the least helpful and encouraging, and the former wants to be helpful but frequently is not aware of the wider scope of services available to the child and parent outside the realm of the immediate school-community situation. Hence, the child and his parent are operating with an incomplete knowledge base in securing the fulfillment of needs.

Finally, a fourth problem that exists is the fact that within the realm of the vast services available there is a dark, mysterious void which, for want of a better name, can be called the "crack" into which many multiply handicapped children fall.

The parameters of this crack are: inappropriateness, financial limitations, age barriers, and non-availability. On one side the parent encounters, "I am sorry this child has a secondary handicap which means he does not fit our program." On another side, "I am sorry but he is too old (too young) for our program." On another side, "I am sorry this child's family makes too much (too little) money to be eligible for our program." And on the last side, "I am sorry but we are full. We will put him on the waiting list for five years hence."

Thus far we have a situation in which the child and his parents have needs which radiate outward away from the family unit. These needs, as indicated, are vital to that child's attainment of maximum potential.

In addition to the complex needs of the child which the parents are faced with there are a myriad of resources and services that exist concurrently outside the family unit. The major problem then focuses on the inability of the family to coordinate and set in motion the whole process of need fulfillment via selection of appropriate services and agencies to meet corresponding needs.

This is the point at which the ecologically oriented agency such as the Texas Elks Diagnostic Center enters the picture becoming the interface between family and environment. Such an agency provides four positive interfacing functions that relate directly to the four major problems encountered by parents:

Parent Problems	Interfacing Functions
1. Parents do not understand child's handicap and subsequent need package.	1. On sight inpatient services which complete necessary diagnostic requirements for understanding handicap, discriminating selection of appropriate services, admission to specific agencies, etc.
2. Parents do not have basal knowledge upon which appropriate decisions can be made.	2. A wide basal knowledge of professional resources and how they function within the local and state bureaucratic system.
3. School and family doctor may not possess adequate knowledge of wide range of services throughout region and state.	3. Serve as liaison with the available services throughout the state opening the door for the individual family to contacts which they have never used before and which they may never use again.

Parent Problems	Interfacing Functions
4. The mysterious "crack" into which many multiply handicapped children fall.	4. Professional knowledge of existing bureaucratic requirements and procedures and ways to quickly circumvent these bureaucratic restraints whenever necessary to secure the most suitable delivery of services to fulfill a child's need package.

(Diagram 3)

To be effective in fulfilling these four interfacing functions it is important that the ecological oriented agency does not itself create a melange of bureaucratic stumbling blocks. The procedural steps through which a child passes in the ecological model should be simplistic efficiency.

At the Texas Elks Foundation these procedures center around five basic phases of service: Referral, Admission, Diagnosis, Planning, and Implementation.

Within the Referral phase the initial referral is received from any agency or individual that might be working with a multiply handicapped child and finds the need for a more expansive view of the child's problem. Appropriate forms are sent and completed. Existing medical, educational, and psychological information is secured to assist in initial comprehension of the situation. Usually some personal contact is made by a staff member with the home either through telephone or a personal visit. An initial intake study is completed by the staff and a decision is made to accept the child for services or refer to a more appropriate agency if the course of the child's need fulfillment is clearly visable and simple to implement.

In the Admission phase the child is admitted to the facility for a residential stay of a few days or six or more weeks. Necessary legal paperwork is accomplished and a preliminary plan for service is completed with the family to state clearly the goals of the diagnostic workup in

Diagram 3

MEDICAL

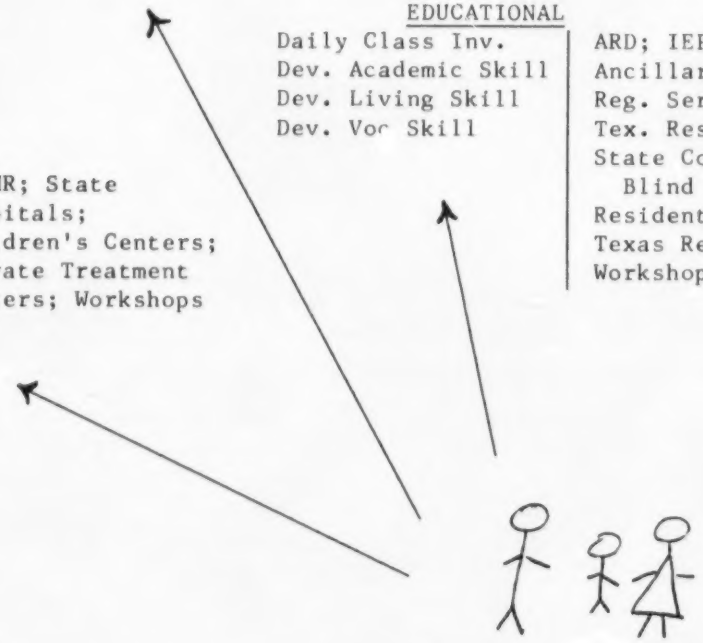
Diagnosis & Eval Treatment Therapy (PT/OT)	Clinics; Med Centers; Rehab Centers; State Comm. Blind & Deaf; State Health Dept; CCD; Medicaid

EDUCATIONAL

Daily Class Inv. Dev. Academic Skill Dev. Living Skill Dev. Voc Skill	ARD; IEP; Ancillary Services Reg. Service Centers; Tex. Resource Services; State Comm. for Blind & Deaf Residential Settings; Texas Rehab. Comm; Workshops

PSYCHOLOGICAL

Diagnosis & Eval Therapy Support Services for Self & Family Unit	MH MR; State Hospitals; Children's Centers; Private Treatment Centers; Workshops



SOCIAL

Peer Int. Community Int. Societal Inv. and Care	MH MR; Day Care; Camps; Parent Groups; ARD; ACLD; ICFMR Programs; CEC; SSI; Medicaid; Y Programs; Dept. Human Resources; Church Groups; Workshops

LEGAL

Fulfillment of rights as a person	Advocacy Inc.; PL 94-142; Sec. 504 Voc Rehab Act (1973); Dept. Human Res.; Workshop

terms of the child's needs as they relate to : a.) parents and family, b.) medical, c.) educational/academic, d.) testing and evaluation and e.) behavioral/social/emotional aspects of the child's behavior. During this short two or three day admission phase the family remains at the center in a separate apartment in order to assist the child in making the transition from home to residential setting. The child receives an intake physical which determines those medical factors that need to be examined.

In the Diagnostic phase the child participates each day in a school program from 9:00 a.m. to 4:00 p.m. under the direction of a diagnostic classroom teacher and several aides. Medical evaluations by consultative specialists in the areas of neurology, otology, ophthamology, orthopedics, etc. are secured according to the preliminary plan developed at time of admission. Arrangements are also made for physical therapy and occupational therapy evaluations and/or ongoing therapy when deemed appropriate. Family counselling sessions are scheduled intermittently during the child's stay and a reasonably close relationship is maintained between the family and the residential facility. Psychological and educational evaluations of the child are done throughout the child's stay. Standardized and objective tests are used along with informational observations from the diagnostic classroom and from individual therapy sessions with the psychologist. The emphasis is on securing a comfortable and adequate picture of the child's true functioning level as it exists 24 hours a day, 7 days a week.

In the Planning phase the preparations are begun for the child's return to his home setting or to residential setting when appropriate. Contacts are made with the family, school, local and state agencies that might be

appropriate in providing a wholistic scope of services to the child. Educational, medical, psychological and community informational bits are gathered together by the staff to begin the final decision-making process. Frequently a consultative visit is made to the school and community to secure first hand information. A final staffing occurs in which the Individualized Educational Plan is prepared addressing itself to the recommendations for home, school, community, etc. A final parent conference is held with the family to present the diagnostic findings and to discuss the future steps and procedures both short term (i.e. immediate school placement) and long term (i.e. long range goal setting and suitable expectation levels for the child's abilities).

In the Implementation phase a comprehensive report with copies of evaluations is completed and sent to the home, the local school, the referring agency and other appropriate resources designated by the family. Another consultative visit may be scheduled to the school in order to assist in the ARD process and aid the family in understanding the local school setting and securing need fulfillment within that school-community setting. Additional counselling and therapy may be arranged for the family and/or child within local community agencies and resources. Additional followup is maintained through further consultative visits, correspondence and telephone contact.

To illustrate how this rather simplistic procedure evolves into a complex ecological interaction, a case history can be used to point out the intricacies involved.

The center has handled some 180 different cases since its beginning in August of 1977, but no case most clearly represents the unique ecological function as that of Jason C.

Jason C. was seen in the facility November, 1977, for a one day initial evaluation. At this time a complete case history and discussion with the parent led the staff to the conclusion that this child could be appropriately served with emphasis on assisting parents and school in securing suitable educational placement.

Jason was admitted one month later in December following the receipt of the complete information from his local school district, his special education cooperative, the regional resource center, and the appropriate medical facilities who has past experiences with this child.

Briefly, Jason can be described as a nine year old profoundly deaf male with such unusual behavior that his educational achievements were severely impaired. Previous educational experiences had involved placement in classes for mentally retarded, autistic, regional day school for the deaf, resource room and homebound instruction all occurring within a four year span.

Following his admission Jason entered a four month diagnostic phase. During this phase a process of elimination was used to determine the central focus for educational services for this child. An evoked response audiometric assessment in a hearing and speech center determined the profound nature of his deafness. A neurological assessment ruled out the possibility of neurological and seizure disorders. An examination of all materials by the Institute for Child Behavior Research in San Diego ruled out the possibility of autism. Extensive and well planned testing at the center determined an intelligence level above that of mental retardation and in the lower levels of normal intellectual functioning. Frequent observations by a variety of persons over some eight weeks of residential placement documented unusual and manipulative behaviors which implied a maladaptive functioning level.

Perhaps most important was the fact that, through a long term involvement in a structured and suitable classroom and dormitory setting, unusual behaviors began to decrease and a more manageable and socialized child began to emerge. With all this information in hand the psychologist established a diagnosis of emotionally disturbed deaf.

While this diagnostic workup was evolving within the facility, an exploration was underway to determine possible suitable educational programing for the child upon his dismissal from the diagnostic center. A consultative visit was made to the state school for the deaf, state school for the mentally retarded, the regional day school program for the deaf in two different cities and his local special education regional resource center, and the Texas Education Agency.

Also entering the picture at this time was Advocacy Incorporated, the non-profit HEW sponsored legal agency in Texas that assists in securing fulfillments of a handicapped child's rights to education. Their role was to become a large one and the Elks center served as liaison agency between lawyer and home providing the professional input as to the scope of the child's problem, suitability of existing services, and proposed services to meet the child's needs.

At the end of several months of involvement with the child and exploration of available services the staff of the center in conjunction with the parents settled on the state school for the deaf as the most suitable placement for this multiply handicapped deaf child.

Jason C. was denied admission to the state school on the basis of his multiply handicapped status. At this point the center moved into another role assisting the legal staff of Advocacy Inc. in preparation of a case.

Assistance was provided to the local district in providing an interim placement for Jason in order to fulfill their responsibility as primary agency in charge of his education at this point in time. The case traveled through several preliminary meetings with staff of the state school and attorneys finally evolving into a full admisistrative hearing before a state appointed hearing officer. At this point the center became the focal source of material evidence and testimony in laying the framework for Jason's admission to the state school.

The hearing officer ruled in favor of Jason C. The issue was bounced to the state commissioner of education following rejection of the decision by the board of directors of the state school for the deaf. Ultimately the decision was upheld and a date was set for Jason's admission to the Texas School for the Deaf.

At this point the staff of the center moved into a different role. Jason was returned to the center for an interim placement where, under the direction of a specially trained teacher of the deaf, the transitional move was beginning for his final admission into the state school. The staff of the center, assisted by the legal staff of Advocacy Inc., provided the professional guidance to the parents in finalizing an acceptable IEP at the state school and completing arrangements for Jason's admission.

On February 19, 1979, some 14 months after the Elks diagnostic center assumed an interfacing role with Jason C., his family, and his environment, Jason was admitted to the state school for the deaf. Last reports indicate satisfactory progression is being made and the family has at last reached some resolution of this difficult experience which has been going on for six years.

This case most clearly represents the complexities that an ecological approach to services can present. It also represents the important advocacy function that such an agency can provide. Only through the on-sight evaluation at the diagnostic center, through on-sight visitation and exploration of educational settings and regional services, and through interaction with available legal and educational services was a meaningful resolution reached. In this case the ecological model involved a broad professional knowledge base, state wide contact and field experiences, and an ultimate objective and individualized concern of "what's right for Jason C." Using these factors it was possible to secure the most realistic and individual placement in the least restrictive setting for a child whose past history was wrought by false starts, false promises, and poor gains.

The center has recently moved into a final new role in this case in that it will now assist the lawyers and parents in continued followup and monitoring of the child's program in the coming years through participation in future review committee meetings.

In addition to these specific advocacy functions, the ecologically oriented agency can provide other salient services to the handicapped child and his family.

During the past two years some four or five workshops have been conducted at the facility. One of these workshops focused exclusively on providing services to multiply handicapped children within the classroom setting in a humanistic and developmentally oriented method. The other workshops have focused primarily on parents and their relationship with their handicapped children. One sought to give parents of severely retarded children some specific guidelines for daily living needs and care; one focused on the developmental delays present in severely orthopedically involved

preschool children; and one centered on managing the emotionally disturbed adolescent who is school phobic and maladaptive at home and school.

Another important function that such a center serves is that of providing one day short evaluations. These one day workups are provided as a type of screening service to parents of children with multiple problems who may not necessarily need a long term residential workup. During these short term evaluations the emphasis is on the staff making contact with the parents and focusing on the pertinent issues relating to the family and its relationship with the child. In some instances medical evaluation may be sought to provide a missing piece to a compl puzzle. In other instances, intellectual screening is performed to give input. In some instances, the need for further workup is indicated and the child is returned to the center at a later time for more comprehensive evaluation. In all instances, though, great effort is made to focus as quickly as possible on relevant problems within the family to assist them in securing some immediate relief in the process of rearing a multiply-handicapped child while beginning to examine more salient long term issues.

Another unique role that the center has played is that of mediator between family and agencies (particularly school). Perhaps the best example of this role of the adolescent school phobic who was referred to the center by a school nurse due to the child's prolonged and unjustified absence from school. After a diagnostic workup and involvement with the family a consultative intervention was made into the school setting.

Through the assistance of the diagnostic center representative a meeting between the school personnel and the family resulted in an honest interchange of feelings and attitudes toward each other. Though great disharmony had existed in the past between the school and family, new lines on communication were opened. The family and the school reached a more

unified approach in dealing with the problems of the child. The child has remained in school and is progressing because of the continued cooperation between home and school. This case indicated in a more concrete way the interfacing role that exists within the ecologically oriented agency.

In summing up, one must look at some very specific factors regarding the ecologically oriented agency: numbers and cost.

During these past two years of its operation the center will have served approximately 180 children with the following breakdown: 37.7% of admissions were less than one week; 10.4% of admissions were over eight weeks; 59.7% of admissions were four weeks or less. This total has been served in a most individualized fashion. No more than 12 to 14 children are in residence at the center at any one time. These children are under the supervision of a professional staff of 7, a child care staff of 12, and maintenance and support personnel numbering 9. The goal has not been quantity as much as quality.

The cost of this service has been approximatley $3,689 per child. Due to the uniqueness of the sponsoring agency, the Texas Elks State Association, this cost was not passed on to parents or school but rather assumed totally by the Elks Foundation. In this way the center could provide a very free, open, and objective service to parents , children, schools, and community agencies without fear of financial manipulative pressure.

The remaining issue to be addressed concerns replication of such a program. It is the opinion of the staff of the center that such a program could be implemented very easily in other states, or better still, within communities. Replication with some modifications could easily be made

by local school district, special education cooperatives, regional resource centers, or regional cooperatives.

It is also possible that it could be replicated within the framework of medical school and facilities which would require that the medical profession move into acceptance of the vital role played by education, psychology, and family in the rehabilitation of a disabled child.

* *

An ecological model for service and advocacy for handicapped children encompasses many things. It is a meaningful inter-relationship of varied resources and agencies at the local, state, and federal level. It is a focusing upon the generic program. It is an attempt to match the unique needs of the child to the myriad of available services and resources. It is most of all, a blending of disciplines into a wholistic approach of service delivery and need fulfillment to the handicapped. A marriage must occur between many different education, psychological, and medical disciplines in order to provide the unique viable program that is inherent in the ecological model.

April 25, 1979

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